DOCUMENT RESUME

ED 413 990 PS 025 587

AUTHOR	McCrea, James M.
TITLE	Talking with Children and Teens about Alzheimer's Disease: A Question and Answer Guidebook for Parents, Teachers and Caregivers.
INSTITUTION	Pittsburgh Univ., PA. Center for Social and Urban Research.; Pittsburgh Univ., PA. Generations Together.
SPONS AGENCY	Pennsylvania State Dept. of Aging, Harrisburg.
PUB DATE	1992-06-30
NOTE	67p.; "With Beverly Americus, Victoria Cotrell, Beth L. Deely, Ruby Hord, Sally Newman, Sue Shupp, Mary Agnes Spampinato, Angela Conrad Staub, Trudy Wachs, Janet Wilson."
AVAILABLE FROM	Generations Together Publications, University of Pittsburgh, 121 University Place, Suite 300, Pittsburgh, PA 15260; phone: 412-648-2209 (Publication No. 138, $12.50).
PUB TYPE	Guides - Non-Classroom (055)
EDRS PRICE	EDRS Price MF01 Plus Postage. PC Not Available from EDRS.
DESCRIPTORS	Adolescents; *Alzheimers Disease; Elementary Education; *Family Relationship; *Frail Elderly; *Health Education; Intergenerational Programs; *Older Adults; Preschool Education; Special Health Problems
IDENTIFIERS	Adolescent Attitudes; *Questions

ABSTRACT

Professionals in the fields of nursing, education, health care, recreation, and social work, who specialize in dealing with Alzheimer's disease, wrote answers to questions collected from discussion sessions held at four Pennsylvania elder facilities and made suggestions for talking to young people about the disease and its impact. This guidebook presents those answers to commonly asked questions to help parents, teachers, and caregivers address issues pertaining to Alzheimer's disease. The questions are grouped into seven categories: (1) discussing Alzheimer's disease with preschool and school-age children; (2) dealing with questions about personality changes; (3) raising awareness of Alzheimer's; (4) coping with behaviors such as dress and personal hygiene, physical and verbal behavior; (5) understanding memory loss; (6) responding to the Alzheimer's adult, and discussing issues such as fear embarrassment, resentment, compassion and empathy; and (7) social interactions, such as involvement and relationship with the Alzheimer's adult. In addition to the questions and answers, the guidebook describes recommended intergenerational activities which can be used with Alzheimer's adults either in a group or one-on-one. Finally, the guidebook provides an annotated bibliography of books for children and youth, preschool to 12th grade, relating to Alzheimer's disease, as well as videos and media information. (Contains 66 references.) (AA)

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Talking with Children and Teens about Alzheimer's Disease: A Question and Answer Guidebook for Parents, Teachers and Caregivers

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An Intergenerational Studies Program
University of Pittsburgh
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PS 025587

June 30, 1992

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Talking with Children and Teens about Alzheimer's Disease: A Question and Answer Guidebook for Parents, Teachers and Caregivers

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Acknowledgements

The vision, enthusiasm, and cooperation of Generations Together's partners has contributed immensely to this project. Their assistance in developing programs, conducting focus groups, asking and answering questions, and writing is greatly appreciated.

We thank the following persons for their help in producing this handbook:

Children's Family Center/Messiah Village
Mechanicsburg, Pennsylvania
Sue Shupp
Angela Staub
Jody L. Brandt
Heidi A. Curry
Bonnie Millary
Charlene S. Yocum

Council Care
Pittsburgh, Pennsylvania
Trudy Wachs
Wynne Gilden

Homewood-Brushton Community Improvement Association
Pittsburgh, Pennsylvania
Ruby Hord
Christine Gale
Angela Ford

Jewish Community Center
Pittsburgh, Pennsylvania
Beverly Americus
Nancy Weitzman

St. Joseph's Youth Group
Verona, Pennsylvania
Rev. Kevin Dominik
Mary Beth Poland
David Demhey
Melissa Donoghue
Jamie Moroney
Jennifer Poland
Megan Rogan
Maureen Scuro

School of Social Work
University of Pittsburgh
Victoria Cotrell

Woodside Place
Oakmont, Pennsylvania
Sue Smith
Beth L. Deely
Mary Agnes Spampinato

Generations Together also thanks the staff, residents, clients, children and families of the following agencies:

Children's Family Center/Messiah Village
Council Care
Homewood-Brushton Community Improvement Association
Jewish Community Center
Woodside Place

Special thanks to Generations Together staff: Nina Alyousfi, Jeff Elinoff, Lili Recchio, Thomas Smith, Chris Ward, and Helen M. Wilson.

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I. Why This Handbook?

"Mom, why does Grandpa call me Mike when my name is Phil?"

"Dad, why do you go see Grandma everyday? Can't you come to my baseball games?"

"Mr. Jones used to be so friendly. Now he doesn't talk to me anymore. Why?"

"What is wrong with Mrs. Snyder? I can't understand a word she is saying."

"How can I help Granny? I want to help her!"

How do we respond to a child who fears his grandmother who is suffering from Alzheimer's disease?

What do we say to a child who no longer feels love from her grandfather?

Which words can help restore these broken generational connections?

More importantly, which words can help keep these connections from breaking?

What can we say to young ones to break through the fear and hesitation that comes in the presence of a person with dementia?

How can we enable them to better understand and interact with these people in a caring and compassionate way?

We hope *Talking With Children and Teens about Alzheimer's Disease: A Question and Answer Guidebook for Parents, Teachers and Caregivers* will help you to answer these difficult and perplexing questions, easing the apprehensiveness that your own children, or children with whom you work, feel when they are together with an older person who has Alzheimer's disease.

Why this Handbook?

Although increased understanding may not completely eliminate the young persons' feelings of uneasiness, it can help them gain confidence in their ability to communicate with older persons with dementia in a more trusting and empathetic way. This understanding will help make it easier for young people to express their acceptance and love for those with Alzheimer's disease.

Generations Together gathered information for this handbook with the help of four Pennsylvania agencies which serve persons with Alzheimer's. Three of these agencies-Children's Family Center, Council Care, and Woodside Place-have intergenerational programs. These agencies are part of a continuing Generations Together effort to develop and expand intergenerational program models that bring children and youth together with persons with Alzheimer's.

These programs and this handbook reflect our belief at Generations Together that intergenerational experiences, including those between young people and older adults with Alzheimer's and other dementias, promote growth and understanding between the generations.

II. Understanding Alzheimer's Disease

The following song uses actual words and phrases expressed by persons with Alzheimer's disease. We hope it inspires you, as it has those of us who created this handbook, to better understand Alzheimer's from the point of view of those who live with this devastating illness.

I was all alone inside, wondering why oh why;
I've forgotten just the 'way to be', could this really be me.
Then you, you came along beside me,
You, you came along to guide me,
You, came along when I needed you most.

In my eyes you saw the pain, how within I was ashamed;
But, now through it all, you caught my fall;
And, so now I'm whole again.
'Cause you, you came along and loved me,
You, you came along and helped me,
You, you came along when I needed you most.

To my friends and family, yes this, is really me;
Now I feel it inside,
I am filled with so much pride,
'Cause you, you came along and loved me,
You, you came along and helped me,
You, you came along when I needed you most.

'Cause you, you are my family,
Yes you, you are the one I need,
And I just want to say thank-you,
Thanks for being my friend.

© 1989 Susan M. Knechtel

(Reprinted with permission from Susan Knechtel, an Activities Director who works with persons with Alzheimer's disease at Council Care Adult Day Care Center in Pittsburgh.)

Reading the lyrics to the song by Ms. Knechtel is one way for the young to understand Alzheimer's disease. Another way is to encourage the young to ask questions and talk about the answers. The first two questions most asked by children and teens are:

What is Alzheimer's disease?
Can I get it?

Alzheimer's disease is a progressive, chronic disease which attacks the brain. Physicians diagnose it by ruling out any reversible conditions which resemble Alzheimer's disease, including such common occurrences as malnutrition, drug reactions, and problems with metabolism.

Forgetfulness with a loss of recent memory is often Alzheimer's first symptom, followed by the inability to perform tasks, disorientation, apathy, and then the inability to communicate effectively. Progression of the disease varies, but eventually people become incapable of caring for themselves. The lifespan of an Alzheimer's person can range from three to twenty years. Unfortunately, it is always fatal. Alzheimer's disease is not contagious and affects only a small percentage of the population, about 10% of those over age 65.

In the early stages, symptoms such as forgetfulness can be compensated for and it is difficult for others to tell that a problem exists. As the disease progresses, memory loss and disorientation become too great to compensate for, and they become apparent to others. Language deteriorates from being merely ambiguous in the beginning to being irrelevant, incomplete, and sometimes nonexistent in the later stages. An individual's personality remains intact well into the middle stages of the disease.

In later stages, the person becomes less able to respond intimately and is less concerned for others. Many practical losses such as the ability to dress, bathe, or find one's way stem from a profound loss of memory and recognition, and a disconnection between key parts of the brain. At this point, awareness of grooming and social behavior usually deteriorates. When inappropriate behavior occurs it is usually due to confusion or misconception. However, violence and inappropriate sexual behavior are not characteristic of the disease.

Individuals with Alzheimer's disease respond to intellectual loss in a number of different ways depending on their past personality and social situation. Most have to deal with lowered self-esteem and a loss of identity, including the loss of familiar roles. In addition, most are aware of their losses at least some of the time and on varying levels. Some react with anger and paranoia while others become depressed and withdrawn. Some individuals are able to work through their dismay before they become too confused. In many cases, the response of the afflicted person to the disease is more difficult for family and friends to deal with than are the actual symptoms.

The cause of Alzheimer's disease is not known. Extensive research is being done to identify the cause. Although there is some evidence that there may be a genetic disposition to Alzheimer's disease, other factors such as viral infection and external toxins are being studied to determine if they influence whether or not a person is vulnerable to the disease. At present, there is no effective treatment for the disease, although many drugs are being researched. In some individuals, medications may help reduce symptoms such as sleeplessness and depression. However, *the most effective response is a supportive, caring environment.*

To improve the quality of life for those affected by this disease, we must keep them a part of our lives. Children and youth can and do play a vital role in the lives of those with Alzheimer's. They can be the teacher, the leader, the listener, the facilitator, the companion, the friend. In fact, a 1990 Generations Together study showed that older adults with dementia demonstrated consistent positive behavior in the presence of young children during music activities that were not displayed when children were not present (Blockstein, Newman, Riess, Tolge, & Ward, 1991)). We and our children should think about the things the person with Alzheimer's disease can do and try to minimize the things they cannot do well or at all.

Even after the disease has robbed Alzheimer's persons of their intellectual and physical capabilities, we must remember that they are still human beings who have feelings. We can help to restore their sense of well being by understanding and accepting their feelings, by having compassion and patience, by showing kindness and love, and by recognizing it a disease over which they have no control.

III. Glossary

Acting Out-To exhibit a radical change in behavior such as swearing or striking someone.

Alzheimer's Disease(AD)-Pronounced **Altz**-hi-merz, a progressive, chronic disease which attacks the brain and results in impaired memory, thinking, and behavior, including a decreasing ability to perform daily job and social activities.

Alzheimer's adult/person-Someone afflicted by Alzheimer's disease.

Apathy-The absence of emotion or concern on the part of the Alzheimer's person.

Awareness-Knowledge of one's own identity, surroundings, and situation.

Briefs-Protective undergarments worn by adults (not referred to as diapers).

Caregiver-Family members and friends who take care of Alzheimer's persons.

Degenerative process-an irreversible deterioration of organs such as the brain, resulting in physical impairment.

Dementia-Deterioration of intellectual performance that involves memory loss and interferes with normal living. Alzheimer's disease is one form of dementia.

Disorientation-A loss of one's sense of time or space.

Hoarding-To accumulate by saving or hiding.

Incontinence-The inability to control one's bladder or bowel.

Inhibition-Restraint of a behavior based on social or moral boundaries.

IV. How We Arrived at the Questions

The questions included in the next section were collected from discussion sessions held at four Pennsylvania elder facilities. Two of these facilities were participating in new or expanded intergenerational programs developed by Generations Together and one has a history of programs between young children and impaired older adults.

Teens from the youth group of St. Joseph's Catholic Church in Verona, visited each week for ten weeks with residents of Woodside Place, a personal care facility for people with Alzheimer's disease. The teen volunteers met to discuss their experiences at three different times during the program. In these sessions, we recorded the questions they raised about Alzheimer's.

At the Jewish Community Center's Early Childhood Program in Pittsburgh, the children traveled each week to Council Care Adult Day Care Center to join its clients in music therapy and arts and crafts activities. During these visits, the staff recorded the children's questions and reactions. When the children returned to the Jewish Community Center, the staff talked with them about their experiences with the elders.

At the Children's Family Center in Messiah Village in Mechanicsburg, young children visited with Alzheimer's residents. The Family Center has been an integral part of the Village for over ten years.

Finally, Generations Together staff convened discussion groups for family members of clients and residents of Council Care Adult Day Care Center, Homewood-Brushton Community Improvement Association Adult Day Care Center, and Woodside Place. Similarly, the Children's Family Center staff questioned families of the Messiah Village Alzheimer residents. The group members shared questions which their children, grand-children, and, in some cases, great-grand children were asking of them about Alzheimer's.

V. Questions From Children and Teens

Preface

The following questions are among those most frequently asked by children and teens who interact with Alzheimer's persons and by the children, grand-children, and great-grand-children of these Alzheimer's persons. By answering these commonly asked questions, we hope to give you information that you can use in discussions with young people of any age.

As they try to understand Alzheimer's and learn how to deal with older people who have the disease, young people should be encouraged to continue to ask questions about what is happening and about any problems they may be experiencing. They should also have the freedom to express their feelings openly, without any fear of feeling stupid or of being scolded.

As you talk with them, respond to what they want to know when they want to know it. Try not to overwhelm them. Finally, in your discussions, be sure to ask young people for their help and suggestions. They may have clever and appropriate ideas that you may not have thought of about how to solve problems .

We have grouped together the questions gathered from the four sites by characteristics associated with Alzheimer's disease such as memory loss and behavior changes. The answers follow in narrative form. For many groups of questions, we suggest responses for you to use or to adapt and suggestions on how to talk to children and teens. This handbook is written informally, as if we were speaking directly to you, the parent, teacher or other adult. While the answers and responses are addressed to parents, they can be used equally effectively by teachers, activities directors and volunteer coordinators.

Professionals in the fields of nursing, education, health care, recreation, and social work, who specialize in dealing with Alzheimer's disease, wrote the answers to the questions and made the suggestions for talking to young people. They intend these answers and suggested responses to be used for general information. In addition to these answers we have included in Section IX, references that provide more detailed information. This section includes an annotated bibliography of books for children and youth, pre-school to 12th grade, relating to Alzheimer's disease. Also, at the end of this handbook we describe recommended intergenerational activities which you can use with Alzheimer's adults either in a group or one-on-one.

Discussing Alzheimer's Disease with Preschool Children

Since preschool children are likely to react to an Alzheimer's adult through their behavior instead of through direct questioning, ways to offer help to children of this age are discussed in the section entitled "When There Are No Questions".

Discussing Alzheimer's Disease with School-age Children

Emotionally, school-age children may seem to resemble Alzheimer's adults. Because of their normally short attention span, children's moods can swing rapidly: angry or grumpy one minute, playing happily the next. School-age children are also easily frustrated, and are still developing the self-control necessary to keep from hitting, pushing, or yelling at someone who is making them angry.

Because they are still learning about feelings themselves, children may find the emotional behavior of Alzheimer's adults especially confusing. School-age children need supportive adults who will take the time to discuss their reactions, help them identify their own feelings, and explain those of the Alzheimer's adult.

You can prepare for such a discussion by gathering pictures or masks showing specific emotions: happy, sad, frightened, grumpy, surprised, and so on. Using these props, tell a story that illustrates some of these feelings and the events which may cause them. Move then to a discussion of "Grandma's" feelings and behavior. Explain to the children that, because of a special illness that only some older persons can get, "Grandma" may show many different feelings all in the same day. You may also ask them how they feel when they are sick, pointing out that illness can cause feelings that are not related to events in the normal way. Explain that "Grandma's" illness will not let her always have "good" or "happy" feelings.

Any talk about bad feelings should include things that help the child feel better. Perhaps they could identify a favorite toy or stuffed animal that they find comforting. Suggest that such an object might help "Grandma," too; maybe they could share it with

her, or maybe you and the child could go shopping together to find "Grandma" her own teddy bear.

When discussing Alzheimer's disease with school-age children be sure to use simple, non-technical terms. Use examples with which the children can identify, but *remember to maintain the dignity of the adult when making comparisons with children's behavior.*

For a school-age child, your explanations must be as concrete as possible. Use examples of safety and comfort from the child's world to illustrate the condition of Alzheimer's adults. For example, the child may still need help with difficult tasks like tying shoes, cutting things, and putting on clothes with small buttons; so too, does "Grandma," because of this special illness that older people may get. Also talk about the fearful feelings that the child might experience when crossing the street, or becoming lost in the supermarket. Relate these feelings to those of "Grandma," who doesn't like being alone in stores or on streets now, either. In "Grandma's" case, of course, it is her illness which prevents her from feeling safe when she is alone.

School-age children also understand what happens when they injure themselves, by falling off a wall or scraping their knee on the playground. Use the children's comprehension of their own experiences to explain that because "Grandma's" sense of balance has been affected by the disease, she could fall and get hurt. Therefore, "Grandma" needs to be kept safe by the members of her family, much the way children's parents work to keep them safe.

Being careful not to burden the children with responsibilities that are beyond their capabilities, find ways for them to feel helpful to "Grandma." Tell them that their presence alone is comforting; like a favorite blanket or toy, they help "Grandma" feel OK.

Finally, encourage children to give "Grandma" hugs, hold her hand, and smile. Remind them that the Alzheimer's person still loves them, and that they can show their love by hugging, kissing and showing that they care. As with the teddy bear purchase, find ways for them to participate in the care of the sick person.

Discussing Alzheimer's Disease with Teenagers

Teenagers have many conflicting needs and emotions to deal with as they pass through the confusing and ambivalent stage of adolescence. While their own feelings may produce a strong emotional reaction to an Alzheimer's adult, they also provide a way to help them relate to "Grandma," who is herself experiencing confusion and mood swings. Teenagers, of course, will eventually grow out of this, but "Grandma's" condition will not go away. Alzheimer's will continue to change "Grandma's" usual responses into unexpected or even unpleasant ones.

By pointing out the similarities that exist between an Alzheimer's adult and an adolescent, a teenager may be helped to understand that "Grandma" may cry, yell, be angry, laugh, stare, or withdraw at any time for no apparent reason. Explain that since she cannot communicate as she used to, she cannot tell them what is wrong or right and is often unaware of her own behavior.

When discussing Alzheimer's disease with an adolescent, you may use precise terms, but be ready to define or interpret if the teen shows signs of not understanding. Continue to use concrete explanations and examples whenever possible. It is recommended that you be direct when explaining the effects of the disease on "Grandma's" abilities. Discuss the areas of movement, memory, emotions, language, and hearing that will be affected over time. Teens can be helped to master their own feelings about all of this through an active coping mechanism: tell them all the ways in which the Alzheimer's adult will need their help.

Adolescents can learn appropriate caregiving techniques, such as distracting or comforting "Grandma," if shown how. Ask for the teen's assistance with specific activities, such as creating large, black print words on cards to help "Grandma" remember things like chair, salt, bed, closet, and bathroom. Teens can assist Alzheimer's adults to and from various rooms, or spend time with them doing planned activities.

If you include teens in discussions and planning sessions, as a respected member of the family, their feelings of resentment will be minimized. Such feelings will not be totally eliminated, however, and your acceptance of the teenager's negative feelings, and your honest acknowledgment of your own, will enable everyone to cope more effectively with the Alzheimer's adult. It is also helpful to discuss the notion of accepting "Grandma" as a person, despite her new "differences." Like younger children, adolescents can be encouraged to continue to express love, warmth, and caring.

Questions about Personality Changes

When children and teens interact with a relative or older person with Alzheimer's, they may notice changes in the person's personality over time. Since questions about personality are common, it is important that they are answered directly. Young people must also understand that the Alzheimer's adult is often unaware that any changes have taken place and that the disease and not the young person is the cause of any mood swing or personality change in the adult.

Typically, young people asked questions relating to personality change such as:

Does personality change because of the disease?

If they are quiet now, were they quiet before the disease?

Why do some of their personalities differ so drastically?

Why is he very friendly and energetic now, when he was quiet before?

One resident wanted to walk around by herself before but, now she likes to talk and walk with people. Why?

The personalities of people with Alzheimer's disease are as unique and as varied as those of people who are not sick. Although personality may change with the disease, not all Alzheimer's adults have the same personality and not all change drastically. Alzheimer's disease can magnify personality traits that were present before the disease. For example, if a woman was quiet before the disease she may become even more so with the disease. However, since Alzheimer's disease can also change personality, this quiet woman may become loud and offensive, or a very social woman may lose her sociability as a result of the disease. These changes occur because of damage within the brain which destroys personality. As a result, Alzheimer's disease robs its victims of who they are and who you know them to be.

Why do some people with Alzheimer's disease:
- **look happy one minute and sad the next?**
- **appear relaxed and pleasant while others with the disease do not?**
- **look grumpy with other residents but friendly with us?**

Everyone responds differently to illness. Because this response reflects each person's unique personality, there are as many differences in people with Alzheimer's disease as there are in all people. Some are pleasant or relaxed while others are not; some are happy while others are sad. These personality differences may also be the result of other illnesses. For example, someone who appears sad may be suffering from depression. In addition, memory loss, a hallmark of Alzheimer's disease, can cause emotions to change rapidly.

Why do some people with Alzheimer's disease like to join in the activities, while other just sit and want to be left alone?

Some people with Alzheimer's disease withdraw from life while others do not. Sometimes they want to be alone while at other times they like to be around people. This illustrates the variability of the disease. Sometimes you can encourage people with Alzheimer's disease to participate by smiling and behaving in a friendly, caring way. However, brain damage may cause persons with Alzheimer's disease to forget the rules of the activity and they may not be able to join in for long periods of time. However, just because they forget easily and cannot stay still for long is no reason not to include them. They still feel pleasure, happiness, and love.

Why is Granpa's personality so different from day to day?

Will his personality continue to change as the disease progresses?

Why do Alzheimer's adults seem so emotional?

Alzheimer's adults will often continue to respond as they did before the disease, but in some cases their emotional responses may be exaggerated. On the other hand, they sometimes react in

opposite ways from their personality because the emotional center of the brain can be affected by the disease. Attention spans may also change. As a result, the emotions can vary as rapidly as attention varies.

The Alzheimer's adult may no longer respond to past social inhibitors of inappropriate behavior. An inhibitor, such as public ridicule which one usually expects when suddenly singing out loud in a public place, may no longer restrain an Alzheimer's person. They may also act toward others in ways previously thought unacceptable, such as swearing in public at a family member.

The emotional responses may also be a result of frustrations and anger about their loss of self-esteem, of their memories, and of language abilities. Some emotional swings are a result of fears and anxieties. Often, Alzheimer's adults feel both up and down at the same time or at inappropriate times. Sometimes, they even know an emotion is inappropriate but cannot stop it.

In later stages of the disease, you may notice what appears to be an "emotionless" stage where no response or feeling is expressed.

Alzheimer's adults will also not be consistent in their emotional responses to everyone. To some, they will react positively to others, negatively. This is not a reflection on the individual or any past relationship, and it is often an indiscriminate behavior. Too much emotional and mental stimulation in the Alzheimer's environment will also affect their emotional reactions.

One way to help Alzheimer's adults deal with alternating emotions is to return your response in a gentle, reassuring voice and manner. Keep in mind that they have little control over these emotions.

Questions about Awareness

Changes in the personality of an Alzheimer's adult can have a serious effect on children and teens unless the young people understand that they are not the cause of these changes. Questions and discussion about personality changes often lead to questions about awareness. Understanding awareness will enable the young person to develop an attitude of caring and empathy for the Alzheimer's adult.

Does the person with Alzheimer's disease realize what they are doing?

Are they aware of what is happening to them?

Do they know that they have Alzheimer's disease?

Do they put themselves down about it?

Do they know if they like or enjoy the activities?

Do they know that they live here now?

Early on in the disease the affected person may realize what is happening and that they cannot do things that were once easy to do. Some people realize that they may have Alzheimer's disease. This realization often leads to sadness or depression and low self-esteem. In most cases, they are aware of what they like and are still able to enjoy activities. As the disease progresses, however, awareness decreases and persons with Alzheimer's disease may not be aware of how they are affecting others and may be confused about where they live.

Should you tell someone that he has Alzheimer's disease?

No. The decision to discuss the diagnosis with an Alzheimer's person is made between that person's family and physician. Until this decision is made, it is best not to talk about it. If the family and physician feel that it is appropriate to talk about

Alzheimer's with the affected person then you can inform the young person of this decision.

Early in the disease however, the person with Alzheimer's disease may realize something is happening to them. This realization can be very frightening. To help decrease this fear you might help Alzheimer's persons focus on strengths and the things they can do instead of those they can't. Since Alzheimer's disease has no cure, *our goal is caring not curing.*

Questions about Behavior

In the beginning, questions about behavior will be among the most common questions expressed by children and teens. These are the "Why" questions. Understanding the stages of the disease and how it affects the brain will enable the young person to deal with changes in behavior. This section answers questions about three kinds of noticeable behavior: Dress; Physical Behavior; and, Verbal Behavior.

Dress and Personal Hygiene

Why does Grandma wear so many dresses at once?

Why does she put the same clothes on every day?

Why do some of the residents have a fascination with jewelry?

Why does Grandma carry her purse all of the time?

Why does Grandpa wear "diapers" and have a potty in his room?

Persons with Alzheimer's disease may have lost the ability to think clearly about what they wear. They have no idea that they wear the same clothes every day or dress backwards or wear so many dresses at one time. They may have a favorite color dress and will want to wear it every day. They like to make choices about what they will wear, just like some children do. They, too, may show a fascination for pretty things and favorite things. Perhaps a particular piece of jewelry reminds them of a part of their past and is therefore very important to them. It may also be a "security blanket" for them, just like a blanket or teddy bear may be for someone when they are young. On the other hand, an object like jewelry, or their desire to carry their purse may be simply be a sign of something they liked to do before the onset of the disease. Holding a familiar object is comforting and helps the older adult feel secure, a behavior experienced by young children.

Sometimes persons with Alzheimer's have a problem controlling themselves when it is time to go to the bathroom. The disease may leave them with little or no control of their bladder or bowel. If so, they wear something called a "brief" (not a diaper) to help protect their clothing.

> *Ask the young person, "Do you know how babies can't control themselves? They have to learn to control their bladder and bowel." Explain that Alzheimer's adults did learn to do so when they were young but now their muscles have lost the ability to control their bladder and bowel. Point out that "incontinence" describes that loss.*

In matters such as hygiene, remember that Alzheimer's adults still need their privacy. You must allow them that space as much as possible and respect their needs. You must treat them with dignity.

Physical Behavior

Why does she shake?

Why do they like to:
- **-walk around a lot?**
- **-wander, even wander into other people's rooms?**
- **-hold your hand?**
- **-follow you from room to room?**

Why do they take things that don't belong to them, or go through other people's drawers and hoard whatever they've taken?

Why can't Grandpa dress himself anymore?

Why is she afraid of the dark?

Why did he rip up the card I gave him?

Why does Granny cut up her dress?

Why does she sing loudly in public places, like a mall?

Why did she go to church on Thursday instead of Sunday?

Sometimes people with Alzheimer's have other diseases such as Parkinson's disease, a progressive nervous disease characterized by muscular tremors or shaking. They may also act differently because of the medication they are receiving.

Alzheimer's adults may like to walk around or wander. They may even go into other people's rooms because they can't remember which room or space is theirs. They may take things that do not belong to them or go through other people's drawers because they don't remember what is theirs and what is not. Sometimes they even take things and hide them someplace special (hoarding) because they to like to collect things just like other people collect baseball cards or Barbie dolls. Collecting particular items may make them feel good even though they may not remember they have them or where they put them.

In their wandering, persons with Alzheimer's may like to hold your hand or follow you from room to room. Knowing that someone is there for them makes them feel secure. They may not want to be alone, just as other adults and children don't like to be alone.

The disease reaches a stage where Alzheimer's adults are not able to follow through on all of the steps necessary to wash and dress themselves. They cannot make all of the connections in their brain to complete tasks that they were once capable of doing. In the earlier stages of Alzheimer's, a care-giver or nurse can help them with these activities by giving them simple step-by-step directions about what to do. In more advanced stages of the disease, they cannot be given too many directions at once. Directions need to be given for one simple task at a time and repeated several times.

Alzheimer's adults may get confused in the dark when things look different. Alzheimer's adults often cannot remember what things are in a dark room; therefore they can become frightened. For example, when it gets dark, furniture and lamps and clothing look different; but, after we think about it, we can remember that, "Oh, yeah! That's the lamp or that's the dresser with my baseball hat on it" and then we may not be so frightened. Alzheimer's adults can no longer think through that process so the unfamiliar shapes in the dark, are frightening.

Alzheimer's adults often like to rip or cut up things, including gifts or cards given by loved ones. This behavior may be the result of tension, feelings of loss or depression, or changes in the brain. They may just need an object on which to focus excess energy. It is important to try and determine the reasons; sometimes the cause can be eliminated. For example, if the behavior is caused by stress or tension then you may be able to reduce or eliminate the causes of the stress.

When they rip a gift or card, they don't remember the person who may have just given it to them and often they are unable to make the emotional connections they used to, therefore the card or gift does not have any special emotional value. They don't mean to hurt anyone's feelings. Loved ones and friends must try to remember the way Alzheimer's adults were before they got sick with this disease and remember the love they shared then. Although Alzheimer's adults may look the same on the outside, their brain is changing and causing them to act differently.

Alzheimer's adults may sing loudly in public places such as a mall possibly because they like to sing but they don't realize that their behavior is not appropriate for that location. Although it may be embarrassing (after all, even children do embarrassing things in public from time to time) singing out loud in the mall is not such a horrible thing. Perhaps you need to accept their behavior.

If Alzheimer's persons mistakenly go to church on Thursday instead of Sunday, it is because they are confused about what day of the week it is. You need to be glad that they remembered and wanted to go to church and how to get themselves there. It is quite common for Alzheimer's adults to be mixed up about which day of the week it is since time loses its meaning for them.

Try to focus on what persons with Alzheimer's disease can do. By building on strengths, rather than weaknesses, you can help bring about a higher quality of life for Alzheimer's adults. For example, include activities which enhance self-esteem and their sense of belonging such as giving them the opportunity to nurture and show affection to a child or letting them help with simple chores.

It is very important to try to remember what these persons were like before they got Alzheimer's. Tell your children who they were and what they did in their lifetime before they were affected by the damaging effects of this disease.

Verbal Behavior

Why doesn't the Alzheimer's adult understand me?

Why doesn't she answer me? She takes so long to answer, and then, if she does, she answers a question that was asked earlier in our conversation.

Why can't she listen and understand what I tell her to do?

How do I respond to the Alzheimer's adult who is talking to me, but not making sense?

What can I do when the Alzheimer's adult keeps asking the same question over and over again, even if I changed the subject?

Why does he make strange noises?

Why does Grandma swear?

Why does Grandma yell at mommy all the time, even though I know that she loves her?

In all stages of Alzheimer's, the ability to "hear" or take in language and process it for understanding, as well as the ability to communicate back, is diminished. The disease also causes inappropriate verbal behavior.

Depending on which area of their brain is affected, Alzheimer's adults begin to experience difficulty with spoken and written language very early in the disease. Often Alzheimer's adults feel a vague fogginess which can make them appear as if they do not hear you. Their ability to respond quickly is also affected. Alzheimer's adults no longer have the ability to fill in "missing pieces" as do well adults. By the time they hear what you have said, they have lost the first part of the conversation. The speed and tone of your voice, as well as the content of your conversation affects their ability to "hear" and to comprehend. What they were doing prior to your conversing may affect how well they understand you because the Alzheimer's mind cannot always do two things at once.

With the progression of the disease, comprehension skills become severely impaired. The more complicated the conversational context, the more difficulty Alzheimer's adults will have in understanding or in answering. Thus, they can become confused if given a question or task that demands an immediate response.

Similarly, articulation skills become impaired. Persons with Alzheimer's may understand conversations but no longer be able to act upon what is said. They may repeat sentences and phrases over and over, getting stuck on certain ideas. Alzheimer's adults may not answer you when you speak to them because they are unable to gather their thoughts into understandable words. Remembering words and putting them together in a coherent fashion becomes increasingly more difficult as the disease progresses.

In later stages, both comprehension and articulation skills will be affected. Alzheimer's adults may babble and use nonsense phrases, or not speak at all. These adults do not realize that they are babbling and not making sense. Persons with Alzheimer's may make strange noises. This may be for a host of reasons: They may simply enjoy making noises or they may no longer be able to produce the words to accurately express how they feel. Perhaps they are trying to put words and sentences together, but because of the disease their brain is unable to complete these tasks. They are often unaware that they are making strange noises in their effort to communicate. In addition to the loss of comprehension and articulation skills reading and writing abilities also decrease.

> *It's best to respond with affection. Continue to talk with them even though you don't understand the attempts at communication.*

Sometimes Alzheimer's adults swear. This may be a sign of frustration or perhaps it is just something they've heard all their lives and it is spontaneous. Sometimes even children and adults say the wrong things when they're frustrated, and children sometimes repeat swear words simply because they've heard other people say them.

Alzheimer's adults may frequently yell at relatives or caregivers even though they love them because the Alzheimer's adults forget who these people are and may be showing frustration with the disease. They don't realize they are not talking appropriately.

> *Ask the young person how frustrated they feel when they can't remember something. Alzheimer's adults may show definite signs of frustration, especially in the early stages of the disease as they become more and more unable to remember people, places, and things and are aware that this is happening to them.*

Young children sometimes get frustrated with their parents over a certain issue and scream, "No" or "I hate you!" Parents know that these children deeply love them and still have outbursts of frustration over the situation. Being upset or angry with someone doesn't mean they don't like or love them anymore; it is simply a way of expressing feelings. Likewise when Alzheimer's adults lose the ability to express their feelings appropriately, those around them must learn to be patient and accept these outbursts as an indication of the effects of the disease and try not to take the yelling as a personal insult or rejection.

Questions about Memory Loss

Along with questions about behavior, children's and teen's questions about memory loss are very common. Since everyone experiences memory loss at one time or another, these questions are especially valid. It is important that children and teens understand the causes of the memory loss and realize that it is not a part of normal aging.

Why don't they remember things?

Why do they go off a subject so quickly?

Why do they only forget certain things?

They talk about family a lot. Is this because it is something they feel they know about or is there another reason. For example, is it the content of the memory or the frequency of it that enables them to remember it?

Why can they remember things from long ago, but not remember what they just said?

Do they ever forget who they are?

Why does she forget so easily?

Some residents were able to remember more than others. Is this because the disease progresses at its own rate?

Why don't they get frustrated or confused about not being able to remember?

While some forgetfulness is normal and experienced by every one from time to time, when the forgetfulness begins to affect one's daily life there is cause for concern. Brain damage caused by the disease is responsible for the progressive memory loss experienced by the Alzheimer's adult. Since the memory loss is gradual, the way it affects Alzheimer's persons varies. They may remember things that happened long ago but not something that occurred five minutes ago. They may remember things which are

more familiar to them such as family and friends. However, eventually they lose even these memories as a result of their brains' inability to make the connections necessary to remember certain things. In the early stages, the Alzheimer's person may be aware of his or her memory loss and be frustrated or confused about it but memory, along with their own identities, will be stolen from them by the disease.

Remember, however, that even though persons with Alzheimer's may not recall what occurred yesterday, they are fully capable of enjoying the "now". They can enjoy and need your love, hugs and touches even if they don't remember them later.

Why doesn't she recognize me?

How do they feel about their families?
Do they remember them?

Can they remember people they knew
before they were affected?

Why couldn't Mrs. Jones remember me?

Why do most residents remember their
families while others do not?

Do people forget about their families?
Mrs. Smith forgot how many children she had.

Why can't she remember my name even though
I spent two days with her and did all of this work?

The way Alzheimer's persons remember people, places and things is not any different than the way they remember other aspects of their lives. There are individual differences in memory ability. One person may be able to recall that a teenager visited them the other day while another person cannot remember the visit. This reflects the stage of the disease being experienced. In general, because of the damage to their brain and the progression of the disease, there will be variances in the way people are affected. Not all Alzheimer's persons experience the same degrees of deterioration as the disease progresses.

Why doesn't grandma bake cookies anymore?

Why can't grandma sew anymore?

Will they remember the activities we did today such as bowling?

When I asked Miss Doe if she wanted a drink of water she said yes but when I brought it she didn't want it and she walked off. Why?

Alzheimer's affects memory gradually. The ability to perform activities such as cooking and sewing, which require a number of events to be done in order, declines when Alzheimer's adults forget one of these events or their sequence. For example, they may forget an ingredient in a recipe or how to thread a needle; frustrating experiences for people who formerly derived much pleasure from such activities. In the early stages, the Alzheimer's adult may be assisted by having written steps to follow. In the later stages, Alzheimer's persons may still enjoy the activity if it is done together with someone else.

Once again, it is important to point out that even though Alzheimer's persons may not remember making pudding or going bowling they are still able to enjoy the activity while they are doing it.

Questions about Responding to the Alzheimer's Adult

After the young person has a basic understanding of Alzheimer's disease and how it affects people they may begin to think about interacting with and responding to the Alzheimer's adult. The questions which follow deal with fear, embarrassment, resentment, and, most importantly, compassion and empathy.

Fear

Is it safe for children to visit the Alzheimer's adult?

How can I help children not react with fear to the Alzheimer's adult?

If the Alzheimer's adult yells at or hits the child, what could you teach the child to do?

In the beginning stages of the disease, Alzheimer's adults often realize what is happening and become depressed or irritable or both. Because they know what is happening but cannot control it, they will often act out the frustration by yelling or by hitting.

As the disease progresses, Alzheimer's adults worry about financial security, emotional and mental well-being, safety, and whether or not their family and friends still love them.

Eventually, the disease begins to destroy the persons sense of self. The Alzheimer's adult may hold onto "things" more obsessively and act out more in frustration and fright. This acting out behavior, along with changes in appearance, movements, emotions, and memory can be very frightening to a young person.

It is important to explain Alzheimer's to the child in terms appropriate to his/her level of understanding. Tell them that this adult is not to be feared but rather to be given extra love and care.

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Reassure the child or teen that this fearful and aggressive behavior of "Grandma's" is caused by the disease itself. It definitely is still "OK" and, in fact, very important for youth to visit, be friends with, and help with the Alzheimer's adult.

Often children can have a calming effect on the Alzheimer's adult. Once children are told the reasons for the Alzheimer's adult's new behaviors, they are eager to help.

Encourage the children to tell the Alzheimer's adults "I love you ", to hold their hand, or give them a hug.

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Why do you still want to be friends with your grandpa when he keeps repeating himself?

Do we have to tell anyone about Granny?

Children and teens are often embarrassed when a parent, relative, or friend acts differently than the "acceptable" norm, because they are vulnerable to peer's opinions of them and their families. A grandparent or other adult with Alzheimer's disease may display many behaviors that others make fun of. When communication skills break down, Alzheimer's adults often become obsessive. These obsessions can show themselves in repetitious behaviors which cause embarrassment for young children.

It is important for the child to know that behavior such as spouting out nonsense, babbling, or repeating phrases, words, or sounds over and over again are caused by the disease.

Be sure to acknowledge the young person's embarrassment and let them know it is OK to feel embarrassed. Help the young person understand the "why?" of these behaviors and then explain that "Grandpa" is still "Grandpa" but that he has a disease now. He cannot control his behaviors. Discuss this with your children and their friends. Ask them if they stop being friends when one of them gets sick? Remind them that "Grandpa" needs them as friends now more than ever.

Children should be informed that other people also understand what Alzheimer's is and recognize why the Alzheimer's adults' behavior differs from other people's behavior. When children realize that other people understand the cause of the behavior of Alzheimer's adults the children will be less likely to feel embarrassed.

Others will be able to feel less embarrassed too, if a direct explanation is given for Alzheimer's disease behavior rather than your attempting to hide or not tell anyone about "Granny" or the facts about the disease. Often friends will become sympathetic and may even want to help, especially if they knew the older person before the disease.

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Resentment

Why don't you have more time to spend with me instead of with Grandma?

Why is Grandma or Grandpa jealous of my time with you? She wants all your attention.

Why do we have to move all my things to make room for Grandma?

Care of Alzheimer's adults requires a great deal of time and watchfulness. As you spend more time with them, children will naturally feel left out.

> *Tell the child that the disease creates a need for constant assistance in Alzheimer's persons. This is the reason you must spend a great deal of time with them. Tell the child that Alzheimer's persons feel anxious and confused, and might get lost, fall or forget important information. They may even forget the lay-out of their room or where a specific room is. Consequently, although you want to spend more time with the child, you cannot leave the adult alone.*

Sometimes, too, Alzheimer's adults will feel comfortable only when you are with them. They frighten easily so it may appear as if they are "jealous" of the child's time with you. They may need the reassurance of your presence and the attention you give them. They may get lonely more easily, too. Insecurity and disorientation are basic behaviors of Alzheimer's adults.

The environment must be carefully arranged for Alzheimer's adults' safety and comfort and one specific area of the house may be more suitable than others. Thus the family may lose their own routines and space in order to create a modified, simpler routine for their Alzheimer's relative. As the disease progresses, and Alzheimer's adults can no longer live alone, basic activities such as washing, brushing teeth, and eating become difficult and some activities such as driving become impossible. They will need constant help and guidance about every aspect of their lives.

Compassion and Empathy

How can we help the Alzheimer's adult?

Should we treat the Alzheimer's adult like a child?

How do you tell the Alzheimer's adult not to do something that might be harmful or non-beneficial without sounding negative?

The most helpful way to treat Alzheimer's adults is with care and compassion. Your first priority is to treat them with respect. Allow them the dignity they deserve. These afflicted adults are not childish, useless old people. They are ill and have lost many survival skills.

When you address them about any difficult situations or inappropriate behaviors, the same courtesy should be extended to them as to others. Speaking in a gentle, firm voice and using a gesture of warmth is reassuring to them.

As the disease progresses, Alzheimer's adults lose their ability to break down tasks into smaller units. They can become driven to keep on a task even if harmful. If you try to stop or interrupt, they may continue even more obsessively or raise their voices.

Remind people that in these situations it is good to try to re-direct their attention or gently remove them to another area. Taking walks, reading to them, singing or doing a familiar hobby with them are all caring ways to respond. Remember: simple tasks, one at a time, done with someone present.

Questions about Social Interactions with the Alzheimer's Adult

Depending on the stage and progression of the disease, the Alzheimer's adult may display varying levels of interest in social interactions and activities. The following questions deal with involvement and participation in activities and with building relationships.

Involvement and Participation

Why do some Alzheimer's adults not want to participate in the activities, but other Alzheimer's adults are so active and want to get involved?

Do we (the family, caregivers, visitors) affect the Alzheimer's adult's behavior, attitudes, or reactions by visiting and getting them involved in the activities?

Are the residents who have more family visits the ones who are more cooperative and more involved?

No one can predict how the disease will affect Alzheimer's adults socially. In general, if they were "joiners" prior to the onset of the disease, they will continue to be so. If they were "loners", they will not necessarily want to join in. However, the disease sometimes alters personality characteristics. Someone who was a loner may become a joiner after the onset of the disease. The environment and what is available to them in that environment will affect the level of their social involvement. In the early stages, it is important to have many choices of physical, social, visual, and mental activities available for them.

As the disease progresses, however, fatigue and extremes in stimulation will negatively affect Alzheimer's adults ability to participate in activities. They often need familiar places and routinely scheduled events to function well. As they begin to lose the ability to break down tasks into smaller units it helps to break into "steps" or sequences any activity that is difficult.

As physical and motor skills decline, participation in some activities may become more difficult. As a result, involvement may get more and more sporadic.

Frequent family visits can add to Alzheimer's persons' positive response to join in activities. It is important to respect their choices and wishes concerning their involvement. If the activity is not liked or seems childish, they may not wish to participate. Like all of us, the Alzheimer's adult may just have no interest in specific activities and not want to participate. Respect this and do not force participation. Be sensitive to the size of the group that visits. In many situations, a person with Alzheimer's disease is more comfortable with a small number of people (1 or 2) to interact with at one time.

Relationships and Social Interactions

Does the Alzheimer's adult who used to get along with a family member now not get along with them and vice versa?

Can an Alzheimer's adult get used to people and become close to them?

Do Alzheimer's adults feel more comfortable with us because we've been with them before?

Why are some Alzheimer's adults more receptive to people while others are hesitant?

Why does an Alzheimer's adult let one person help them such as by tying their shoes but refuses to let another person do the same thing?

With all that is happening to the adult because of the disease, relating and socializing become more and more difficult. Sometimes Alzheimer's adults will respond better to professionals trained in the disease. At other times they may prefer familiar family members. Alzheimer's adults can still develop familiar close relationships with others during some early stages. Family relationships will fluctuate during the disease progression; Alzheimer's adults may get more and more irritated or more attached and dependent on family members.

Alzheimer's adults often respond to some association they share with a person. Therefore, one person may receive a positive response while another receives a negative response. Alzheimer's adults often do not distinguish between people.Their behavior reflects their mental mood and is not necessarily related to the friend or family member.

It is always important when relating to Alzheimer's adults to tell them your name first. This saves embarrassment and can help the Alzheimer's person recall the associations. The Alzheimer's adult will find it easier to relate in smaller groups with less stimulation. In general, the Alzheimer's adult responds to respectful, caring interactions and can appreciate other people.

VI. When There Are No Questions

Usually, children are naturally curious when entering a new situation or meeting new people. They ask many questions. At times, no questions are asked, but children are aware that something is wrong or different. It is during these times, such as when children are around people with Alzheimer's disease, that adults need to briefly explain what is happening to the older adult. "Even small children can benefit from an honest explanation of what is happening to the person with a dementing illness - in language they can understand." (Mace and Rabins, 1981)

> *Say to the child, "If Grandma doesn't remember things as well as she used to, we may need to help her." Or, "If Grandpa talks very loudly to you, he is not angry with you, but forgot to use his inside voice."*

If you are taking a group of children under five years of age to visit a group of memory impaired seniors, prepare the group for the visit using dramatic play, storybooks and pictures of seniors. Discuss with the children the attributes of the seniors and also the disabilities. Review what will take place during the visit. After the visit, ask for questions, and if there are none, ask some questions of your own and talk about any unusual behavior that has occurred. Listen carefully for a child to drop a few words that indicate a concern or a question. Comments are sometimes made after the visit.

Once children understand that Grandma or the seniors they are visiting have an illness, they can help to care for, and grow to understand persons with Alzheimer's.

VII. Conclusion

We hope this handbook helps you to discuss Alzheimer's disease with the children in your life. We also hope the answers and responses are useful to you in these discussions.

We encourage you to keep the lines of communication open between you and your children and to use this handbook as a basis for further discussions and reading about Alzheimer's disease. We also encourage you to foster the continuing relationships between young persons and older persons with Alzheimer's. The benefits to both parties, including increased self-esteem, responsibility, and confidence make intergenerational activities well worth the effort.

VIII. Intergenerational Activities

Because concentrating and following directions may be difficult for Alzheimer's adults, activities including simple daily tasks such as bathing and brushing one's teeth can become a challenge. Therefore, when planning activities, we recommend that you start with a few goals in mind. Try to choose a variety of activities which utilize the skills and abilities of the Alzheimer's person. Choose tasks that are dignified and enjoyable for the person and which involve others. Try not to focus on the results but on the experience itself. Finally, be flexible. Be open to the older adult's responses and adapt your activities to their needs.

The following activities represent simple experiences which have been tried, tested, and recommended by experts in the field. They can be conducted with no training and little preparation and most are adaptable for either individual use or in a group. They can be done at home or in an adult day care center or other facility.

General Activities

Art Experiences (higher functioning)

- Color simple pictures
- Paint on large pieces of paper
- Work with clay
  - Create a simple sculpture
  - Have a sample to show
  - Break down the steps involved

- Create Calendars
  Include:
  - The date
  - The weather-symbols like sun, umbrellas, wind, etc.
  - The season
  - The time - morning, noon, evening, night

Music Experiences

- Create rhythm bands with spoons or other household implements, or musical instruments such as drums, rhythm sticks or tambourines
- March to music

- Dance - Bunny Hop, Hokey Pokey, Square dance

- Sing favorite hymns, songs, or simple melodies
  - For lower functioning people sing in their ears as you move their fingers or hands to the rhythm or words

Story Time Experiences

- Use a felt board with story characters cut out. Place the characters and props on the story board as you illustrate the story. Repeat stories often.

- Read poems. Simple, rhyming ones are best Repeat often. Use the adults favorites, if you know them.

Memory Experiences

- Memory Box
  - Collect many objects Alzheimer's persons can identify with. Remove them one at a time and discuss the memories evoked by each object.

- Review Photo Albums
  - Discuss events and persons in the photos and help the Alzheimer's person maintain a connection with the persons in the photos.

Physical Exercises

- Stretch to music
- Lead chair basketball
- Conduct scarf exercises
  - Have the Alzheimer's adult hold one end of the scarf and a child or other adult hold other end. Turn the scarf in circles, up and down, right and left, etc.

Social Experiences

- View videos of old television shows and movies
- Tape their favorite book, poems, memories, and stories.
  - Use slow pacing, gentle, familiar voices.
- Provide head phones and a Walkman and teach the steps for their use.
- Encourage them to work on a computer. This experience helps recall words and phrases. They can often recall language on the computer more effectively than through the spoken orwritten word.
- Go for walks
- Go out for a meal
- Go on picnics
- Cook together

Specific Activities

The following are examples of activities which are broken down into steps. They are all appropriate intergenerational activities. The Balloon Toss, Castle and Puppets, Parachute Dance, and Table Bowling are more suitable in an institutional setting but can be adapted for home use if you have the required materials. Making Pudding, Sing Along, Tell Me a Story and A Thousand and One Words can be done at home or in an elder facility. The writers of this handbook selected these recommended activities.

Balloon Toss

Description: Adult and child sit opposite each other and toss a balloon back and forth to each other.

Number of Children: 1-10 Number of Adults: 1-10

One-on-one activity? Yes Group activity? Yes

Materials needed: Blown-up balloons

Approximate time required: 2-5 minutes

This experience involves physical movement of all participants.

Practical considerations: If toss is done to music, tape or record player required.

Castle and Puppets

Description: Paint a castle and puppets with an adult and child paired up to work together on a section of the castle and then the puppets.

Number of Children: 11 Number of Adults: 11

One-on-one activity? Within group. Group activity? Yes

Materials needed: 6foot long by 3foot wide cardboard, paint and sponge brushes, faces drawn on poster board and glued to tongue depressors.

Approximate time required: 2- 1/2 hours per session

This experience involves children helping the adults with the project and conversing and interacting throughout.

Practical considerations: This project requires staff to participate since it is a messy activity.

Making Pudding

Description: Children and adults make pudding. Add milk to powder, take turns stirring (everyone gets ten times to stir), enjoy eating.

Number of Children: Any Number of Adults: Any

One-on-one activity? Yes Group activity? Yes

Materials needed: Box of instant pudding, large bowls, mixing spoons, plates and spoons.

Approximate time required: 20 minutes

This experience is an enjoyable activity that produces conversation between adult and child. Also a very good snack!

Practical Considerations: Make sure pudding is cool enough to eat.

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The Parachute Dance

Description: Participants sit on chairs in a circle. Each person holds on to the end of a parachute while a beach ball is tossed into the center. the participants move their arms slowly up and down creating their own dance. Children may sit under the parachute, bouncing the ball from underneath.

Number of Children: 4-12 Number of Adults: 4-18

One-on-one activity? No Group activity? Yes

Materials needed: Parachute or large sheet, 1-2 pre-chosen songs, tape or record player, balloons or beach balls.

Approximate time required: 30 minutes

This experience focuses on interaction, socialization, creativity and concentration as well as slow movement. Enhances gross and fine motor skills, sequencing, mind/ body stimulation, and helping hands. Good as a beginning activity- touching without touching!

Sing Along

Description: Adult and child sing familiar songs together such as "Take Me Out to the Ballgame", "Old MacDonald", and "You Are My Sunshine".

Number of Children: Any Number of Adults: Any

One-on-one activity? Yes Group activity? Yes

Materials needed: Tape or records are useful but not required.

Approximate time required: 2 minutes+

This experience may bring back pleasant memories for both adult and child. They can enjoy each other in a positive way.

Practical Considerations: This activity may become noisy. Be sensitive to any response of the Alzheimer's person that suggests anxiety.

Table Bowling

Description: Set up 10 plastic bowling pins at one end of a table. Adult and child stand at the other end and take turns knocking down the pins with a plastic ball.

Number of Children: Any Number of Adults: Any

One-on-one activity? Yes Group activity? Yes

Materials needed: 2- 4foot tables, plastic bowling set.

Approximate time required: 30 minutes

This experience allows adults and children to enjoy an activity together that is fun and encourages conversation and interaction.

Practical considerations: Must have sufficient room away from breakable objects.

Tell Me a Story

Description: This activity involves children and adults sharing written stories by reading to each other. Can also be used to include personal made-up stories. For a selection of children's books, see the annotated bibliography at the end of this handbook.

Number of Children: 1-10 Number of Adults: 1-10

One-on-one activity? Yes Group activity? Yes

Materials needed: Childrens books; poetry; funny, happy, sad, or scary stories.

Approximate time required: 10-30 minutes

This experience involves socialization, teaching, learning, self-esteem enhancement (both youth and elder).

A Thousand and One Words

Description: As a picture is worth a thousand words, the sharing of personal pictures between children and adults is worth a thousand and one!

Number of Children: 1-10 Number of Adults: 1-10

One-on-one activity? Yes Group activity? Yes

Materials needed: Pictures, background information, memory books/wallets, etc.

Approximate time required: 10-30 minutes

This experience involves caring, sharing, feeling useful, self-esteem enhancement, conversation, and reminiscing.

Practical considerations: Have as much background information as possible.

IX. Resources

There are many resources available to families and friends of those with Alzheimer's disease. This list focuses on those resources which may be useful to adults who wish to discuss Alzheimer's disease with young persons. It is not meant to be all-inclusive.

Organizations

To locate services in your area, contact:

Alzheimer's Association, Inc.
70 East Lake Street, Suite 600
Chicago, IL 60601-5997
800 621-0379

American Association of Retired Persons
1909 K Street, NW
Washington, DC 20049
202 434-2277

American Health Assistance Foundation
15825 Shady Grove Road, Suite 140
Rockville, MD 20850
800 227-7998

Benjamin B. Green-Field National
Alzheimer's Library and Resource Center
919 North Michigan Avenue, Suite 1000
Chicago, IL 60611-1676
312 335-9602

The French Foundation for
Alzheimer Research
11620 Wilshire Boulevard
Los Angeles, CA 90025
213 470-5462

The National Council on the Aging
409 3rd Street, SW, Suite 200
Washington, DC 20024
800 424-9046

National Institute on Aging
Alzheimer's Disease Education
and Referral (ADEAR) Center
PO Box 82250
Silver Spring, MD 20907-8250
1-800-438-4380
301 495-3311

Pennsylvania Council on Aging
Alzheimer's Disease Clearinghouse
231 State Street
Harrisburg, PA 17101
800 367-5115

Children's Books Pre-school to Grade 6

A beautiful pearl. Whitelaw, Nancy.(1990). Morton Grove, IL: Whitman. unp. ISBN 0-8075-0599-4.
Young Lisa narrates the story expressing her desire that Grandma wouldn't be sick with Alzheimer's disease anymore. The story focuses on her grandmother's inability to remember where she put Lisa's birthday present, a pearl for a necklace. When Grandma finds the pearl, she and Lisa share a fleeting glance of recognition and a moment of love. Judith Freidman captures the spirit of the book through realistic illustrations set on marbled paper. The book contains a brief note from the author about Alzheimer's disease. (grades 3 - 6)

Always Gramma. Nelson, V. (1988). New York: Putnam. unp. ISBN O-399-21542-5.
As Alzheimer's disease overcomes Gramma, a young girl recalls the wonderful times they had in the past. When her grandmother is placed in a nursing home, the young girl visits and sings the songs Gramma taught her. The change in Gramma from vibrancy to blankness is beautifully depicted. Water color drawings illustrate this bittersweet story. (preschool - 3)

Alzheimer's disease. Beckelman, Laurie. (1990). New York: Crestwood House. 48pp. ISBN 0-89686-4898.
Through first-person narrative, the author discusses diagnosis, care, and treatment of her grandmother. The book provides a thoughtful introduction to Alzheimer's disease. The large print and color photographs add to the book's accessibility. A glossary and a list of helpful addresses are appended. (grades 4-6)

Forget me not. Schein, Jonah. (1988). Toronto: Annick. 24pp. ISBN 1-55037-001-4.
Written by twelve-year old Jonah, the book is based upon his experience as his grandmother lapses into Alzheimer's disease. The story is written from the point of view of a young child who comes to understand that grandmother is neither mean nor crazy, but sick. The habits of those in the first stages of the disease is accurately portrayed. (preschool - 3)

Grandma didn't wave back. Blue, Rose. (1972). New York: Watts. 62pp. ISBN 0-531-02557-8.
Every afternoon as she returns home from school, ten-year old Debbie stops to wave at Grandma, who is watching from their apartment window. There are days when Grandma doesn't wave back and Debbie knows Grandma's memory is bad again. Although written in 1972, this tender story is timeless as it portrays the sadness and difficulties faced by a family as a loved one lapses into Alzheimer's disease. (grades 3 - 6)

Grandma's soup. Karkowsky, N.L. (1989).Available from Kar-Ben Copies, Inc. 6800 Tildenwood Lane, Rockville, MD 20852
This storybook for children presents a young girl's experience as she confronts her grandmother's Alzheimer's disease. The story recounts how the grandmother adds inappropriate ingredients to her traditional family soup one evening. The girl's parents help her learn that families need to provide love and understanding to a loved one with Alzheimer's disease. *(preschool-3)*

Grandpa's song. Johnston, T. (1991). New York: Dial. unp. ISBN 0-8037-0801-7.
In this story we meet Grandpa, who always sings with his grandchildren and teaches them a special song. When he begins to have trouble remembering the words to his songs, the children are understandably concerned. They rally though, and sing the words he can't remember. The happy ending may be a bit unrealistic, but the lesson of love extended and returned is clear and moving. (preschool - 4)

Happy Birthday, Grampie. Pearson, S. (1987). New York: Dial Books. unp. ISBN 0-8037-3458-1.
Martha and her family are going to see Grampie, who is celebrating his 89th birthday. Martha makes a very special type of birthday card, hoping Grampie will remember who she is. Find out how Martha achieves this feat. The book is illustrated with warmth and grace by R. Himler. (grades K - 5)

Grandparents: A special kind of love. LeShan, Eda. (1984). New York: Macmillan. 119pp. ISBN 0-02-756380-4.
A valuable book drawn from the author's experience as a new grandmother and her memories of being a beloved grandchild. Special situations are dealt with including when a grandparent changes because of illness. The book encourages understanding between grandchildren and grandparents. (grades 3-6)

Love you forever. (1986). Munsch, Robert. Willowdale, ONT: Firefly Books. unp. ISBN 0-920668-36-4.
This is a story of how a little boy goes through the stages of childhood and becomes a man. His mother nurtures his growth and as his mother becomes old, he becomes the caregiver. A thoughtful book about the enduring nature of parents' love and how it crosses generations. (preschool-3)

Maria's Grandma gets mixed up. Sanford, Doris. (1989). Portland, OR: Multnomah. unp. ISBN 0-88070-298-2.
The book describes one family's struggle with the grandmother's Alzheimer's disease. Maria is a preschool-age Hispanic girl, who begins to wonder, "What's wrong with Grandma?" The first half of the book describes the embarrassment and denial experienced by the family, as Grandma gets lost, wanders around at night, and disrupts mealtimes. The remainder of the book describes the family's efforts to actively cope with Grandma's illness. Although an explicitly religious book, Maria's prayers and conversations with God about her family's difficulties seem proper in the context of this story. (preschool - 3)

The memory box. Bahr, Mary.(1992). Morton Grove, IL: Whitman. unp. ISBN 0-8075-5052-3.
The memory box's poignancy lies in the belief that the old and young generations can preserve and enjoy memories, no matter what happens to the older person. Grandfather, who realized that life was drastically changing for him along unexplained avenues, had the vision to make a way for his grandson to treasure the

memories that they had shared together. As the days passed, the grandson became aware of the changes taking place in Grandfather's body, that Grandfather would never be the same. He sensed and cherished the value of the memory box. (Grades 2-6)

My Grammy. Kibbey, Marsha. (1988). Minneapolis, MN: Carolrhoda Books. unp. ISBN 0-87614-328-1.
Eight-year old Amy learns to be patient with Grammy, who has Alzheimer's disease. Grammy and Amy share a bedroom which makes Amy's adjustment to Grammy quite poignant. This story is fiction, but it is filled with realism as the reader meets a family learning to accept and deal with the disease. The charcoal illustrations by Karen Ritz can assist an adult reader who might have to explain the disease to children.
(preschool - 3)

Grandpa doesn't know it's me. Guthrie, Donna. (1986). New York: Human Sciences. unp. ISBN 0-89885-302-8.
This is a sensitive book, written from a child's point-of-view, of a family's experience with Alzheimer's disease. It begins to answer questions: What is wrong? Will I get it? What do I tell my friends? All the questions are answered gracefully. The book was produced in cooperation with the Alzheimer's Disease and Related Disorders Association and contains "A note to parents" that may also be useful to practitioners. (preschool-3)

My grandma's in a nursing home. Dalton, J. (1986). Chicago: Whitman. unp. ISBN 0-8075-53336
Jason's grandmother has Alzheimer's disease and must stay in a nursing home because she needs special care. Jason is upset at his first visit but continues to visit and adapts well to the patients and the environment. (grades K - 3)

Sachiko means happiness. Sakai, Kimiko. (1990). San Francisco: Children's Book Press. unp. ISBN 0-8923339-065-4.
Grandma doesn't recognize Sachiko any more, which makes Sachiko angry. Sachiko has been given the task of watching Grandma who becomes confused, thinking she is five-years-old, is lost, and Sachiko is a stranger. Sachiko agrees to help Grandma find her home and then begins to understand that Grandma will never be the same. The book is vividly illustrated by Tomi Arai.
(preschool - 3)

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Wilfred Gordon McDonald Partridge. Fox, M. (1985). New York: Kane/Miller Book. 32 pp. ISBN 0-916291-04-9.
Wilfred, who lives next door to a nursing home, has many older friends, and one special friend who has "lost her memory." His small acts of thoughtfulness help her to unlock the stories of her past. The fanciful, soft color illustrations present caricatures of older persons, yet render them with amused tenderness. The hopeful story sheds a positive light on relationships between the young and the old. (preschool - K)

Children's Books Grades 7 to 12

Alzheimer's disease. Landau, Elaine. (1987). New York: Watts. 67pp. ISBN 0-531-10376-5.
The book discusses the early symptoms and diagnosis of Alzheimer's, the effects on the family, and suggestions for coping and care. It contains anecdotal information from family members who relate their own stories, which makes for interesting reading. (grades 6 and up)

Alzheimer's disease: The silent epidemic. Frank, Julia. (1985). Minneapolis: Lerner. 80pp. ISBN 0-8225-1578-4.
Sarah, a hypothetical older woman who is victimized by Alzheimer's disease, is the focus of the book. Medical procedure and progression of the disease are explained through her case. The book is valuable for youngsters trying to understand their relatives who have changed, for ample attention is given to fluctuations in temperament, loss of bodily functions, and such psychological problems as paranoia. A glossary is included. (grades 6-up)

Doc. Graber, Richard. (1986). New York: Harper. 150pp. ISBN 0-06-022064-3.
Brad Bloodworth idolizes his grandfather, "Doc," an eminent physician now suffering from Alzheimer's disease. This candid, serious story brings to light Brad's acceptance of his grandfather's illness, as well as the family chaos that can result from this illness. The story contains references to sex, infidelity, and chemical abuse which makes the novel suitable for the more mature reader. (grades 9 - 12)

A dream of queens and castles. Bauer, Marion. (1990). New York: Dell. 118pp. ISBN 0-440-40554-8.
Twelve-year old Diana moves to England with her mother. The first day she is there she meets eccentric Group Captain Somers, with whom she has a great adventurous journey to London. Although Alzheimer's disease is not mentioned as a direct cause of Group Captain Somers' eccentricity, the characteristics of the disease such as confusion, wandering, and forgetfulness are manifested in Somers' behavior. This is a well-crafted story, filled with memorable characters and vividly created in an English setting. (grades 7 - 12)

In with the out crowd. Howe, Norma. (1986). Boston: Houghton Mifflin. 196pp. ISBN 0-395-40490-8.
In this first person narrative, Robin Tweedy-Boyd, begins to have confidence in herself as she develops a separate identity apart from her reckless friends. Family relationships, including a brief look at the problems and pain associated with her grandfather's Alzheimer's' disease are wonderfully portrayed. The focus of the story lies in the depth and growth of Robin as she establishes her own set of values. (grades 9 - 12)

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Media Information

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